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Re A (Conjoined twins: surgical separation)

An ethical commentary

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The case of the conjoined twins Jodie and Mary and the legal battle that led to their eventual separation is well known.¹ From the outset it is clear that, as both Huxtable LJ and Ost LJ note, there is no obvious *ethical logic* that can resolve this dilemma. However, it is possible to have some ethical reflections on several central concepts on which the judgments of Huxtable LJ and Ost LJ are based. In particular, I wish to raise questions about things that are often taken for granted in cases like this such as issues of language; ideas about the welfare of the child and the inherent complexities of calibrating welfare; the fresh perspective brought to these familiar ethical dilemmas by relational and care ethics frameworks; and the unresolved puzzle of singular and plural embodiments in the lives of conjoineds.

Language

Both judges start by outlining the facts, and much of their later reasoning relies on these initial descriptions. Over the last decade or so there has been a growth of interest in the *rhetoric* of medical ethics and bioethics. Tod Chambers showed that bioethics cases are narrative constructions designed to locate the reader within a particular moral or legal point of view, even if not direct them towards a particular conclusion.² As narratives they are representations of the real world, both contained within and exploiting rhetorical conventions to make different moral evaluations more or less compelling. In the judgments of Ost LJ and Huxtable LJ, this is done less through the overall narrative structure than individual words and turns of phrase. Ost LJ, for example, describes the efforts of the medical team as aiming to “save the stronger twin” [1]; Mary has a “seriously impaired brain, heart and lungs” [2] and faces the “awful prospect” of being “dragged around” by a twin who is developing “normally” [2]. None of this is false, but it takes a significantly different tack from Huxtable’s description, in which Mary “relies on” Jodie’s support, [1] and Jodie “owns the stronger organs” [2] rather than being the stronger twin. These differences are subtle but can influence the identification and evaluation of salient features in delicately

¹ In *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147.

² T Chambers, *The Fiction of Bioethics* (New York, London, Routledge 1999)

balanced dilemmas like these.³

The welfare of the child and the ethics of care

Working within the framework of family law, Huxtable bases his second argument on the primacy of the welfare of the child, and ultimately on children's entitlement to have the law protect their interests and lives [10-15]. In the case of Jodie and Mary, the difficulty is that there are two children involved (in most accounts) and both cannot be equally protected. In terms of medically determinable parameters, Jodie's welfare is best served by separation because she can survive the separation but will die if it does not happen. But separation will inevitably mean the death of Mary, and it is hard (though not impossible) to argue that this serves her welfare. Equally, though, if she is likely to die anyway, the death of Mary is not of itself a decisive ethical factor tipping the balance one way or another.

In medico-legal cases like these the evaluation of interests tends to prioritize things like health and even basic survival. However neither Jodie's nor Mary's interests are exhausted by the predicted clinical outcomes; ([7]) the wider concerns of the surviving child, and of the family in the aftermath of either decision, need also to be taken into account. Ethicists have difficulty identifying these interests, let alone grasping their significance to the different actors in the story to start weighing them up. Since there is genuine uncertainty about what constitutes the best interests and welfare of Jodie and/or Mary, and it is not the doctors or lawyers but the parents (and Jodie and Mary themselves) who will have to live with the consequences, Huxtable concludes that the opinion of the parents should prevail [16]. This argument is pragmatic and compassionate but theoretically rather thin. A more ethically satisfying basis may be found in a *relationally grounded ethics of care*, and more broadly an ethics in which the moral necessities special to familial relationships are taken seriously.⁴

Ethics of care is arguably something of a misnomer: while it describes an approach focused on the moral obligations generated by dependent human animals' needs for care, contemporary care ethics does so less because of an interest in the practice of *care* than because it recognizes the primary importance of (often) asymmetric relationships to moral

³ Chambers (n 2).

⁴ V Held, „ *The Ethics of Care: Personal, Political, and Global* (Oxford, Oxford University Press, 2006) T Pettersen, „ “The Ethics of Care: Normative Structures and Empirical Implications” (2011) 19 *Health Care Analysis* 51–64.; J Tronto, „ *Moral Boundaries: A Political Argument for an Ethics of Care* (London: Routledge 1993).

life. The terminology of care is shorthand for saying that, outside of legal contracts, most human relationships are asymmetric; those relationships that are most emotionally and morally important to us tend not to be the freely chosen coming together of autonomous equals; and special attention must be given to relationships involving care precisely because the giving or receiving of care exemplifies this unavoidable imbalance of power and dependency in human contacts.⁵

Jodie and Mary were utterly dependent on the care given to them by their parents and wider family, as much as the medical care they needed. So the analytic framework provided by care ethics becomes highly salient. Prioritizing care does not resolve the dilemma, but it foregrounds a set of moral criteria that may be obscured by other ethical theories. While any ethical analysis must acknowledge the twins' radical dependency on others, a care ethics perspective gives more prominence to other, less obvious aspects of care, such as the moral importance to the parents of providing the best support to that dependency – the best *kind* of care – and it is not obvious what that means from the parents' point of view. For example, the parents' rejection of surgery is articulated in the judgments in terms of their religious scruples. These scruples are not given close examination. They *might* rest on the teachings of the Roman Catholic church, but they may also be influenced by a more theologically and ethically complex sense that the best form of care for both of their children is through equal acceptance of both children. 'Care' entails something other than the preservation of bare life. In the vocabulary of a contemporary relational ethics of care, it is less about providing for the physical and medical dependencies of the infants than it is about caring for and about existing and future relationships. This might mean taking into account not just the relationship between the parents and their children, but also the one between Jodie and Mary: a relationship which the parents' faith tells them will continue beyond physical death.

A care ethics approach can include other actors who constitute the fabric of relationships in complex medico-legal dilemmas, but whose own moral needs and vulnerabilities are normally less prominent. In this case, we might want to look at the clinical team and other hospital staff. It is important to be clear that acknowledging that medical professionals are involved in various forms of care relationship with Jodie and Mary does not mean that their

⁵ E.F. Kittay and E.K. Feder, *The Subject of Care: Feminist Perspectives on Dependency* (New York, Rowman and Littlefield, 2002).

moral claims have the same weight as those of the children's parents. But it counterbalances the way that in many accounts these other actors appear solely as representatives of a particular clinical option or line of legal reasoning, even when they have their own opinion on, and moral investment in, the right course of action for Jodie and Mary.

Family ethics

Very recently, the focus on relationality and relationships of care in both health and social care contexts has led to a developing "ethics of the family". This approach does not privilege or naturalize the moral claims of families, but it is influenced by the recognition there is "discordance between the sorts of ethical relationships and perspectives that exist within a family, and those that govern the behaviour of the healthcare system dealing with those families".⁶ For instance cases like Jodie and Mary's tend to be approached as a conflict between the medical profession and the family over the fate of the patient. The result of this antagonistic framing is that the ethical imperatives, priorities and tensions of patients' families tend not to be explored in detail until problems arise, especially problems between the families' views and those of the clinical team. In case studies used to teach the ethics of end of life decisions, the patient's relatives commonly only become involved at the point where they question their loved one's decision making capacity, or challenge a clinical care decision; less interest has been shown in the conversations about care these actors (patients and families) may have had long before the clinicians made an appearance.⁷

Persons and bodies

I have not said much about Ost LJ's discussion, largely because its core is about the doctrine of double effect (DDE), and as she notes, this has been debated by moral philosophers and lawyers for a very long time [4]. However, one aspect of Ost LJ's discussion points in a different direction, and although it is not followed up in the judgment it is central to the ethics of this and other cases involving conjoined twins. This is the nature of the *identities* of Jodie and Mary. There remains genuine uncertainty about how many patients/persons are present. This does not just make for a tricky moral dilemma here: it presses against some fundamental assumptions about personhood, individuality, embodiment, and the

⁶ MA Verkerk, et. al. 'Where Families and Healthcare Meet' (2015) 41 *Journal of Medical Ethics* 183-185.

⁷ See eg C Rehmann-Sutter, H Gudat, and K Ohnsorge, *The Patient's Wish to Die: Research, Ethics and Palliative Care* (Oxford, Oxford University Press, 2015).

relationships between those concepts.

In using the DDE in a comparison between delivering analgesics to relieve a patient's suffering (and thereby shortening life), and the separation of Jodie and Mary, Ost LJ mentions Ward LJ's contention that the DDE cannot apply to the conjoined twins as (i) the surgery affects two distinct patients, and (ii) for one of them, Mary, surgery itself is not in her best interests.⁸ Although Ost LJ ultimately disagrees with Ward LJ on this conclusion, she does not challenge the claim that two individuals are present [17]. Similarly Huxtable LJ also agrees with Ward LJ that although Jodie and Mary are conjoined, they are not one individual: "we are determining the fates of two children" [2]. The consensus is there is not one person but two, trapped in an anomalously singular body. If prenatal development had run as it should, Mary and Jodie would have been two individuals in two separate bodies. Something has gone wrong, and surgical separation can put it right. In line with this, the available empirical evidence suggests that in most cases where both conjoineds have undergone normal cognitive development, there are two subjectivities, two persons, present.⁹ This is why surgical separation of conjoined twins is normally undertaken, even when not separating them does not present an acute issue of survival because two persons require two bodies.

Perhaps, though, we do not have a case of two subjectivities unable to step away from each other because they are stuck together in the same skin. Philosophers, especially feminist philosophers, are increasingly paying attention to the phenomenology of embodiment in shaping our moral perceptions and judgements.¹⁰ They argue the kind of body through which we engage with the world also shapes the moral and other stances that we hold towards that world. If so, being/inhabiting a very unusual form of body might generate preferences and priorities that are also to some extent anomalous - it would be hard for

⁸ *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147 (CA) 199 (Ward LJ).

⁹ A Dreger, *One of Us: Conjoined Twins and the Future of Normal* (Harvard, Harvard University Press, 2004).

¹⁰ SL Bartky, *Femininity and Domination: Studies in the Phenomenology of Oppression*, (New York, Routledge, 1990); G Weiss, , *Body Images: Embodiment as Intercorporeality*, (New York and London, Routledge, 1999). IM Young, *On Female Body Experience: "Throwing Like a Girl" and Other Essays*, (New York, Oxford University Press, 2005). See also YM Barilan, 'One or Two: An Examination of the Recent Case of the Conjoined Twins from Malta'. (2003) 28 *Journal of Medicine and Philosophy* 27-44; M Shildrick, 'Some Speculations on Matters of Touch' (2001) 26 *Journal of Medicine and Philosophy* 387-404.

those of us who inhabit standard model bodies to predict these preferences and priorities with any real confidence.¹¹

There is some evidence for this in cases of conjoined twins. Huxtable LJ, drawing on Dreger's work,¹² reports only one example where adult conjoined twins asked to be separated [21]. Even when one twin has died, which would generally mean the death of the other -- the closest analogy to the situation of Jodie and Marie -- separation has not been requested. Adult conjoined twins rarely if ever see themselves as *separable*, even when remaining joined means certain death. This is not a state into which most of us, used to being single persons within a single body, can easily imagine.

Perhaps conjoined twins are better considered as a novel class of persons who inhabit the world in a different way: neither as single persons, but nor as two persons joined by an accident of nature, and who would inevitably be better off normalized through separation. The conjoined body like this has some parallels with a more common variation where the practice of 'normalisation' has attracted recent bioethical attention: the bodies of those born with ambiguous genitalia so that they are not easily identified as anatomically male or female. Until recently the default response to ambiguous genitalia was surgical intervention to 'restore' the baby or child to visible normality. The problem is that tidying up the external genitalia so that they look indubitably male or female is not always consistent with either the internal anatomy, or the later self-perception, of the individual concerned. Conceptually, normalisation is increasingly challenged for being a lazy retreat into binary gender categories; a growing number of bioethicists are arguing for the ontological validity of intersex subjectivities that are neither conventionally male nor female.¹³

If we were to consider conjoined bodies in a similar way, what might be the consequences for the ethics of this case? First, and as I emphasised at the outset, it wouldn't *solve* the dilemma of this specific situation -- in fact it is hard to see what would. But it does open up a space for understanding conjoineds as something other than anomalies that need to be

¹¹ J Leach Scully, 'Moral Bodies: Epistemologies of Embodiment' in H Lindemann, M Verkerk & M Urban Walker(eds), *Naturalised Bioethics: Towards Responsible Knowing Practice* (Cambridge University Press, 2008); J Leach Scully, *Disability Bioethics: Moral Bodies, Moral Difference*, (Lanham, MD, Rowman & Littlefield, 2008).

¹² Dreger (n 7).

¹³ A Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic Books (2000); EK Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine* Indianapolis: Indiana University Press (2014); L Ermer, 'Paradigms Revised: Intersex Children, Bioethics and the Law' (2002) 11 *Annals of Health Law*; 195-236

rescued and restored. Viewing conjoineds as way of being in which two persons are/inhabit a single body is different in important ways from a starting point in which two individuals who *should* be in two bodies are competing with each other for ownership of a single set of structures and organs. As Bratton and Chetwynd note, in a number of historical cases the assignment of internal organs before conjoineds are separated has been arbitrary enough to suggest a psychological need to believe that one twin has a greater right to, say, the shared heart, and therefore a greater right to life, to justify the intervention.¹⁴ Perhaps instead we might think about conjoined twins as two persons in a single body – which, in the case of Mary and Jodie, is an impaired body because of the cardiac insufficiency. Their single body is terminally ill, but still offers both persons the possibility of some life – even a reasonably good quality of life -- in biographies that, at least initially, seemed more acceptable to their parents than the alternative provided by separation.

A second ethical consequence would be to provide an even more compelling rationale for a better understanding of what it is like to live conjoined. Ultimately this would need to come from empirical and experiential work with surviving conjoineds, about how they see the world and their place in it generally but also, crucially, what they think about the question of separation. Would they wish to be separated; do they wish they had been separated earlier in their development; would they want to be separated if the option is death? Do words like ‘separate’ and ‘individual’ and ‘autonomy’ even mean quite the same as they do for non-conjoineds -- and is their alternative meaning sustainable, interesting, and/or useful for the rest of us? Information like this is essential in order for families and healthcare professionals to make decisions that are based on the lives of people whose experience is very different from the statistical norm. In the end, the necessity of gathering information to support ethically justifiable decisions is itself an ethical matter; it is not ethical to make life-changing medical interventions based on inadequate information when at least some of that information is available if only we would make the effort.

¹⁴ M Bratton and S Chetwynd, ‘One Into Two Will Not Go: Conceptualizing Conjoined Twins’ (2004) *Journal of Medical Ethics* 279.